

*Shaw, F. H. -*

*Pages 2-5*

*and page 14 are  
most important.*

*[Signature]*

## Milestones

### I. Terms of Reference

A. This brief was commissioned by the Secretariat Responsible for Disabled Persons, as part of efforts to establish a base for helping Canadians disabled by pollution.

B. The brief compiles, in graph form, a chronology of major milestones in the advocacy effort related to the issues of environmental sensitivity. It includes Federal and Ontario Provincial government responses, and those of some other major stakeholders. While it touches on some concerns relating to the actions of authorities, it is a compilation of successes rather than an expression problems and concerns.

C. The brief does not include a report on actions of provincial governments outside Ontario, although it may be worth noting that Nova Scotia has sent a doctor to Britain for training in clinical techniques.

D. An appendix lists the addresses of major stakeholders. It would be useful and highly recommended that their individual position papers/issue briefs be solicited to complement the experience of the author.

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26 November 1988

*much has happened since, of course.*

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II. A story...

The first eight months of 1985 were a chore...trying to get Health and Welfare to stop defaming people disabled by pollution. Health and Welfare's comments were creating public and institutional bigotry about our sanity, and damages from the misconceptions created remain a bigger problem than the problem itself.

Approaches to the department provoked varied responses: bland acknowledgement of the concern, arrogant rejection, and, in some quarters, downright belligerence. Many public servants declared that our direct experience as human beings (and citizens) was merely "anecdotal".

September that year brought an opportunity to leave Ottawa for a month on a contract as a TV Current Affairs trainer with the Inuit Broadcasting Corporation in Iqaluit, N.W.T. It was a joy to travel over hundreds of kilometers of northern rock, scrub, and lakes, to leave the southern ozone zone far behind. The food up there is still relatively free of the chemicals and antibiotics which pollute commercial food production in the South. Northerners eat frozen arctic char and caribou; the water supply in Iqaluit is spring fed; the air really does smell sweet.

Imagine my disbelief after bunking down in a ground floor apartment, when diesel fumes began wafting in through my window from a construction compressor just outside. I'd travelled two thousand kilometres into the wilderness, into the pristine North, but civilization's pollution lay in wait. Worse yet, as a new kid on the block, I didn't want to be troubling my neighbors with a problem they wouldn't care about, that they would think was just an "unverified claim", even an inconsequential anecdote.

Perhaps they'd heard from Medical Services that the problem was delusive.

After taking a calming walk, I went to IBC editor Henry Nowdluk for advice. He listened attentively as I carefully described the problem, the proximity of the compressor, and the disabling effect of the fumes.

Henry's unhesitating response stunned me: "Did you ask them to move it?"

I confess...after the experience of years of dealing with officials in Health and Welfare, the thought of such a simple, direct, and uncomplicated resolution had not even entered my mind.

### III. Introduction

In reading this brief there are a number of points that should be kept in mind. Although they logically flow out of the developments referred to in the brief, their importance compels their mention at the start.

The reader will probably have had some exposure to media reports on the subject, which may have been misleading. Perhaps laying to rest some popular myths would dispel some confusion.

1. Environmental sensitivity is not one illness, but a term that refers to a "compendium" of disorders and adverse health influences relating to environmental agents, including foods, inhalants, and natural and synthetic chemicals.

2. Sometimes the disorders involve the immune system, but sometimes they may not. Any system of the body can be affected. "Total Allergy Syndrome" is not an inclusive term for the illnesses experienced by people in the group. Allergists and immunologists are only qualified to comment on a segment of cases.

3. The term "Total Allergy Syndrome" is misleading for another reason. Even in patients where there is immune system disfunction, it is as impossible to be "allergic to the whole world" as it is to create a "universal" solvent. (What would you put it in?) "Total" creates the impression the problems are insoluble when in most cases, given co-operation, they're fairly easy to manage.

4. Likewise, the term "Twentieth Century Disease" is misleading. Many of us have problems with such archaic substances as wood smoke, for instance. It is true, however, that the many bio-interactive synthetics introduced in the past few decades present an increased total load on the human organism. Some have speculated that nutrient depletion in soils, through acid rain and agricultural stresses, may have affected human nutrient intake, and, as with trees in toxic-rain forests, reduced our resistance to adverse influences.

5. The controversy in the medical community is not about whether or not some people are sensitive to chemicals, and suffering disabling effects. The controversy is about diagnostic and treatment protocols. It would not exist if the disorders did not exist.

6. For most people experiencing the problem, an environmental sensitivity is as obvious as the cause of a

burn, or cut. Or, as feeling dizzy in a room that's recently been painted, and then feeling better once outside. There is no great mystery to the fact that people disabled by pollution are conscious of what is happening to them, (and worried about it).

7. The history of coming to terms with the problem has echoed efforts to get authorities to deal with the effects of toxic rain on trees. For a time, exuberant expert after exuberant expert came forward explaining that fungi, immune systems, bacteria, viruses, soil, insects, worms, etc were a problem in various forests. Finally, pollution was identified as a common factor. In the case of the environmentally sensitive, as many "causes" have been "proven". Even the victims' consciousness of the effects has been described as the pathological factor; it's funny no-one says trees in a toxic-rain forest are just upset because skies are grey.

8. It is silly to argue over the lay of the land in places where no-one's been. As a provincial committee in Ontario stated, "confidence in the health care system is eroded when productive dialogue between different medical specialties disappears, or is replaced by acrimonious debate", and, "taking an absolute stance in this field is not only risky scientifically, given that there is a great deal that we do not know about our environment and its effects on us, but it is also unproductive and divisive, antithetical to the task of promoting collaborative efforts that will help in understanding the problems of a growing number of patients".

9. The same committee made special mention of how the media has helped polarize debate, stating: "Our unease has been...fueled by media reports that highlight extreme positions". No matter how self-assured health and media professionals may be, each should be conscious of the fact that many professionals have made fools of themselves, causing damages to victims in the process, by claiming understanding they do not truly possess.

10. Many people, both survivors and professionals, have outdone themselves in bringing forward understanding on the issues involved.

#### IV. The Thomson Report

A. Although scientific literature on us goes back at least to 1908, our first big breakthrough with the Ontario Ministry of Health came in 1984, with the appointment of the "Ad Hoc Committee on Environmental Hypersensitivity Disorders" by then Ontario Health Minister Keith Norton. The Committee was chaired by former Provincial Court Judge George Thomson, joined by five professors and doctors of medicine.

B. The Committee suggested that doctors learn to work together, (see III: 8,9 above), and defined the illness as follows:

Environmental Hypersensitivity is a chronic (i.e., continuing for more than three months) multi-system disorder, usually involving symptoms of the central nervous system and at least one other system. Affected persons are frequently intolerant to some foods and they react adversely to some chemicals and to environmental agents, singly or in combination, at levels generally tolerated by the majority. Affected persons have varying degrees of morbidity, from mild discomfort to total disability. Upon physical examination, the patient is normally free from any abnormal, objective findings. Although abnormalities of complement and lymphocytes have been recorded, no single laboratory test, including serum IgE, is consistently altered. Improvement is associated with avoidance of suspected agents and symptoms recur with re-exposure. (p 228)

C. The committee also made thirty recommendations to provincial government, involving retraining for doctors, education in the health community, developing inter-ministerial policies, banning smoking in public places, setting up an ecological control unit to assess testing protocols, other research, and so on.

D. Although the committee recommended further research on tests used by "clinical ecologists", (the term adopted by M.D.s treating patients with the problem), it's worth noting that those tests have since been favorably reviewed in the American Medical Association.

E. More recently (14 September 1988) George Thomson wrote "I have been and remain very dissatisfied with the response to the report on environmental hypersensitivity".

V. Discretionary actions by Ontario Ministries

A. Over the past decade, a number of provincial ministries other than the Ministry of Health began helping people affected in a variety of discretionary ways:

1. Ontario Cabinet Minister Richard Patten suggested the Health Minister meet with people hurt by Ministry of Health statements to discuss damages and further action, (3 December 1987).

2. The Ministry of Natural Resources is providing confiscated game as a source of unpolluted meat.

3. The Ministry of the Environment initiated community-based process in Kinburn, Ontario, to monitor and consider alternatives to weed control chemicals in a neighborhood where several environmentally sensitive people had moved to escape city pollution. The Hon Jim Bradley, Minister of the Environment, has stated: "Environmentally sensitive people are the first to feel the effects of low level contaminants in the environment".

4. The Ministry of Housing is exploring housing alternatives for people with sensitivities, and providing special low-tox units on a discretionary basis.

5. OHIP is paying for some of the more severely affected individuals to go to clinics outside Canada for partial treatment.

6. The Ministry of Community and Social Services provides monetary supplements for people with special dietary needs resulting from the illness.

7. In the Spring of 1986 the Premier of Ontario expressed sympathy for people affected, and made particular reference to two individuals he had been informed about who had committed suicide due to bigotry in health institutions.

8. The former Minister of Health, in a letter to Evelyn Gigantes, M.P.P. (7 October 1986) stated: "recognition of the issues related to environmental hypersensitivity resulted in the appointment of the Ad Hoc Committee on Environmental Hypersensitivity Disorders...in 1984".

9. In response to the statement "The Ministry has been negligent", the Policy Co-ordinator on the subject in the Ministry of Health stated "I know it" (5 June 1986).

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10. Greg Sorbara, the Ontario Minister of Labour, has acknowledged that the illness is "so prevalent these days" that it is being called "Twentieth Century Disease".

11. The Ontario Minister of Agriculture has expressed awareness and a willingness to explore concerns that might relate to his ministry.

12. The Minister Responsible for Disabled Persons has noted the extent of the problem, expressed concern, familiarized himself with a number of initiatives by various ministries and municipal authorities, and agreed to treat the problem as one disabling Ontario residents.

13. The Ontario Opposition Leader and spokespersons on Health, the Environment, the office of the Ombudsman, Human Rights, and other critics have expressed sympathy and concern.

14. The Ontario Human Rights Commission has acted on behalf of a number of victims.

15. The Office of the Ombudsman is familiar with the issue.

16. Three years after receiving the Thomson report, and nearly two years after a request from the Ontario Medical Association, the Ministry of Health announced action on one of Thomson's thirty recommendations (10 February 1989). The Ministry is setting up a research project to investigate medical concerns relating to the illnesses. Unfortunately the committee will be chaired by Dr. Barry Zimmerman, (see 17, next).

17. [I have not included the previous Zimmerman Committee (appointed by the Ontario Minister of Health, Murray Elston), as a "major milestone". There is convincing evidence that Dr. Zimmerman's appointment was unethical, and his conduct irresponsible.]

VI. Federal action

A. There has also been progress at the federal level...

1. The Parliamentary Secretary to the Minister of the Environment, Gary Gurbin, stated in a telephone conversation in early 1986 that the situation faced by the environmentally sensitive was similar to that once faced by epileptics. Skeptics once said epileptics were "possessed by the devil". We were labelled as deluded.

2. Michel Cote, when Minister of Consumer and Corporate Affairs, offered to open discussions with people affected about food product labelling.

3. Flora MacDonald stated in a letter in early 1986 that "Recent statements concerning the dangers posed to human health by toxic rain will assist in arousing public awareness to the problems of the environmentally hypersensitive".

4. Roch LaSalle, when Minister of Public Works, offered to open discussions on any elements of the problem relating to his department (which is responsible for federal government office buildings).

5. David Crombie, as Minister Responsible for the Status of Disabled Persons, wrote the Minister of Health and Welfare asking about "any future plans he has" to address problems we face. Mr. Crombie also helped sponsor a conference of people affected which took place in Ottawa on 4 April 1987.

6. Environment Canada has promised "horizontal policy influence" directed at other departments on the issues raised. Environment Minister Tom McMillan also contributed to the conference on 4 April 1987. One of his chiefs of staff stated "the Minister, Environment Canada's officials, and I have considerable sympathy for the people who suffer health and other problems as a consequence of exposure to chemical substances in the built and natural environments". Environment Canada has suggested that Health and Welfare fund a project on this subject. Mr. McMillan said in a speech that "government cannot wait until science provides irrefutable proof", and, "The departments of Environment and Health were organised at a time when the two policy areas were seen to be much more discrete than we now know them to be", and, "artificial barriers preclude the kind of genuinely interdisciplinarian approaches that the problems in the real world demand".



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7. Tom Hockin has referred the concern to the Minister of Health and Welfare.

8. Stewart McInnis's office has made funds available on an ongoing basis through the Residential Rehabilitation Assistance Program so that people disabled by petrochemical heating in their homes could convert them to electric.

9. Paul Dick has written the Minister of Health and Welfare several times on our behalf.

10. Andre Bissonnette referred the concern to the Minister of Health and Welfare.

11. Barry Turner, Vice-Chairman of the Standing Committee on Health and Welfare, stated in a letter "I intend to raise your concerns with my colleagues in the near future".

12. Mr. Elmer MacKay referred the concern to the Minister of Health and Welfare in 1986, and an official in his office refused to prosecute myself for taking part in an income tax boycott in 1985, 1986, and 1987.

13. The Minister of Health and Welfare, Jake Epp has repeatedly (but privately) stated he is sympathetic to the concerns of people who are ill as a result of sensitivity to chemicals. He has acknowledged that the federal government has responsibilities relating to keeping chemicals from hurting people in the environment. Several people in Health and Welfare have the illness, including a PR spokesperson who once stated that the department did not think sulphites were a problem, as well as the head of the chronic disease epidemiology section of the Laboratory Centre for Disease Control. Health and Welfare made public it's working paper "Healthy Environments for Canadians", written by Bruce Small, in the Fall of 1988, nearly a year after it's completion.

14. Mr. James Kelleher referred the concern to the Minister of Health and Welfare.

15. Mr. Benoit Bouchard has referred the concern to the Minister of Health and Welfare.

16. Mr. Joe Clark has stated (in response to a census boycott), "You are quite legitimately concerned about the emerging problem of environmental hypersensitivity". (Mr. Clark is reported to be sensitive to cigar smoke.)

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17. Monique Vezina added environmental sensitivity to the post-censal survey of the disabled in 1986, and referred the concern to the Minister of Health and Welfare.

18. Mr. John Crosbie referred the concern to the Minister of Health and Welfare.

19. Mr. Marcel Masse referred the concern to the Minister of Health and Welfare.

20. David Kilgour referred the concern to the Minister of Health and Welfare.

21. John Bosley referred the concern to the Minister of Health and Welfare.

22. Ms Pat Carney asked the Minister of Health and Welfare to look into the concern.

23. John Reimer stated he "is in contact with the Minister of Health and Welfare" on this subject.

24. Treasury Board has stated in a letter (26 January 1987) that "Treasury Board, as employer for over 200,000 public servants, will take any necessary action to assist an employee with this condition, as it has many times in the past for employees with other health problems".

25. Reg Stackhouse referred the concern to the Minister of Health and Welfare, twice.

26. Pauline Browes referred the concern to the Minister of Health and Welfare.

27. The Honorable Jean Charest, Minister of State (Youth) referred concerns about the Minister of Health and Welfare's (lack of) performance to the Prime Minister's Office in a letter (8 December 1987).

28. Alan Redway raised the issue in the House of Commons (12 August 1988). He has written the Minister of Health and Welfare on a number of occasions asking him to help. Mr. Redway helped achieve medical tax deductions for the environmentally sensitive, announced 20 December 1988 by Finance Canada.

29. NDP Member Michael Cassidy wrote the Minister of Health and Welfare on the issue of damages caused by irresponsible statements from Health and Welfare, and to Michael Wilson on the need for medical deductions.

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30. Liberal Health Spokesperson Sheila Copps issued a news release (18 December 1987) stating that "the environmentally sensitive suffer reactions to chemicals and compounds in the environment...federal departments should be researching the prevention and cure of this crippling disease", and "I hope it will not take until the 21st Century before this disease is eliminated". Ms Copps has also written the Health Minister a number of times on this subject, and she introduced a Bill on food labelling in the House.

31. Liberal Environment Spokesperson Charles Caccia made a statement in the House of Commons (21 September 1988). "Mr. Speaker, thousands of Canadians suffer health problems because of a distinct sensitivity to food additives, chemicals, and other synthetic substances. Only recently has this been recognized as a physical illness. For example, last year the Ontario Medical Association called on governments to increase research on causes, effects, and treatment of environmental sensitivity, also called the 20th century disease. Individuals, organizations, and even the Human Rights Commissioner have asked the Minister of National Health and Welfare (Mr. Epp) to take action on this serious health problem. Instead of action he has only sympathy. We urge him to recognize the existence of this illness, to instruct his department to become competent in the field, to launch a campaign to educate health professionals, and to consult with those who suffer from environmental sensitivity. In short, we urge him to stop sympathizing and start acting."

32. The Chief Commissioner of the Canadian Human Rights Commission has written the Health Minister (3 August 1988) stating that "We owe it to people who have this syndrome to be more public and more positive in acknowledging that... environmental hypersensitivity is a true medical problem". Mr. Yalden also stated that he considers it "reasonable" for victims to request that "the Health Minister would state publicly that he is sympathetic with the plight of those who suffer from environmental hypersensitivity and considers their concerns legitimate".

33. The NDP Health Critic, Margaret Mitchell, has stated in the House of Commons (Question Period, 26 August 1988) that "environmental hypersensitivity...is a multi-system disorder usually affecting the nervous systems of persons who are sensitive to some foods and chemicals and environmental agents". Ms Mitchell also asked if the Department of Health and Welfare will "undertake a public

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awareness campaign, as well as research, to assist in avoiding and treating this serious and little known ailment".

34. The Standing Committee on Health and Welfare gave a sympathetic hearing to the subject (26 May 1988). One of the Committee members, Paul McCrossan, has chemical sensitivities.

35. Energy, Mines, and resources has deemed that sealed homes must have continuous mechanical ventilation.

### VII. Other institutions

A. The Scientific Editor of the Canadian Medical Association Journal has someone in his family who has arthritis as a result of a sensitivity to medication. Katherine McCourt, spokesperson for the Association, states it is well documented that some people suffer disabling reactions to some chemicals in the environment. The CMA included office building sickness and birth defects due to pesticides in its submission on the federal Environment Protection Act.

B. The Ontario Medical Association has called on the provincial government to fund diagnostic and treatment research, and has distributed materials produced by the clinical ecologists. The OMA has also written the Premier's office stating that "there is a social problem that should be addressed by social agencies in Ontario. The situation is that individuals are ill with a condition that has not been scientifically defined and they are not being well-served in their need for support services. The situation is clearly frustrating for patients, physicians, and government, and requires careful attention to avoid blaming the victim."

C. The Ontario Public Health Association had a forum on the subject 8 May 1987.

D. For the most part, health institutions and medical journals now recognize reality, although some still defend biased, unscientific and damaging articles they previously published on the subject. The CMA Journal, for instance, has not corrected impressions that may have been left by an illogical, misinformed, damaging, and surely therefore unethical article written by psychiatrist Donna Stewart in 1985. (15 November, page 1001).

E. NASA has a wealth of experience dealing with the adverse health effects of low level pollution in (sealed) space vehicles.

VIII. Current media

A. Although some reporters and editors fall into the temptation of reporting polarized stories "highlighting extreme positions" which are damaging to people disabled by pollution by suggesting there is reason to debate our legitimacy, most journalists now realize the problem is real and concerns raised are legitimate. Members of the National Press Gallery organized and resisted attempts to turn their building (150 Wellington) into a sealed building. However, as with Health and Welfare and the Ministry of Health, many media institutions have not undone ongoing damages from previous actions. They haven't corrected previously published or broadcast reports by clearly stating the problem is now considered to be real, leaving many audiences with the memory of previously reported "raging controversy".

IX. Outstanding business

1. Neither the federal or provincial governments have acted to help people hurt by insupportable statements to the effect that victims were deluded. These comments were more of a problem than the problem itself. Families broke up, careers ended, professional reputations were ruined, and some people even became so demoralized by the bigotry fostered that they committed suicide. The people affected by irresponsible statements from the health authorities deserve a hand up now that those comments are understood to be wrong.

2. It would be helpful if Health and Welfare undertook public education to turn around attitudes fostered by their previous statements. Public misconceptions about the illness remain the biggest problem faced by the group.

3. Public education aimed at reaching people with environmental sensitivities who have not yet been diagnosed have been swamped by bigotry fostered by officials. "Rescue" efforts, particularly for chronic psychiatric patients, should be fast-tracked. This effort should receive federal funding to reduce the federal government's liability for damages to those individuals who would have been rescued by now had Health and Welfare not acted irresponsibly for a quarter-century.

4. As mentioned at the outset, groups of people affected have been discouraged after years of ridicule and humiliation by the authorities. In the author's opinion, the most valuable act authorities could undertake would be to solicit representations from both elected representatives and members of these groups on the three points immediately above, and on any other concerns Canadians disabled by pollution feel are important to express.

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X. Appendix - Stakeholders in the issue

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Advocacy Group for the Environmentally Sensitive  
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Ontario M3M 2X1

Allergy Foundation of Canada  
Box 1904 Saskatoon  
Saskatchewan S7K 3S5

Candida Research Foundation  
598 St. Clair Ave. W.  
Toronto  
Ontario M6C 1A6

Clean Air Environmental Allergy Society  
Box 46633, Stn G  
Vancouver  
British Columbia V6R 4K8

Small and Associates  
(authors: Healthy Environments for Canadians)  
RR 1  
Goodwood  
Ontario LOC 1A0

Society for Clinical Ecology and Environmental Medicine  
c/o Dr. Jozef Krop  
RR 6  
Mississauga  
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Human Ecology Foundation of Canada  
(Name change imminent, to)  
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